



First Steps

**Indiana's Early Intervention System
for Infants, Toddlers and their Families**

2004 Annual Performance Report

July 1, 2003 to June 30, 2004

A Message from the ICC Chair, Valerie Strohl

Dear Governor Daniels,

On behalf of the members of the Interagency Coordinating Council on Infants and Toddlers, I am pleased to submit the annual report of the ICC.

During the 2003-2004 grant year, the First Steps system provided services to more than 19,000 children and their families, at an average cost of \$2,900.00 per child, well within national averages for early intervention services. Through the efforts of Eligibility Determination Teams, Peer Monitoring, Accountability and Quality Assurance measures, First Steps growth came in at less than 1% for the grant year.

As the system continues to evolve in fiscally challenging times, First Steps stakeholders will work diligently to hold costs, increase efficiency and contain growth, while simultaneously providing the services necessary to meet the developmental needs of our most vulnerable population.

This report includes a 'fact sheet' section, which reviews the First Steps mission and vision. The remainder of the report is organized around the five themes by which our activities are measured:

- ◆ **Child Find**
- ◆ **Supervision**
- ◆ **Family-Centered Services**
- ◆ **Natural Environments**
- ◆ **Transition**

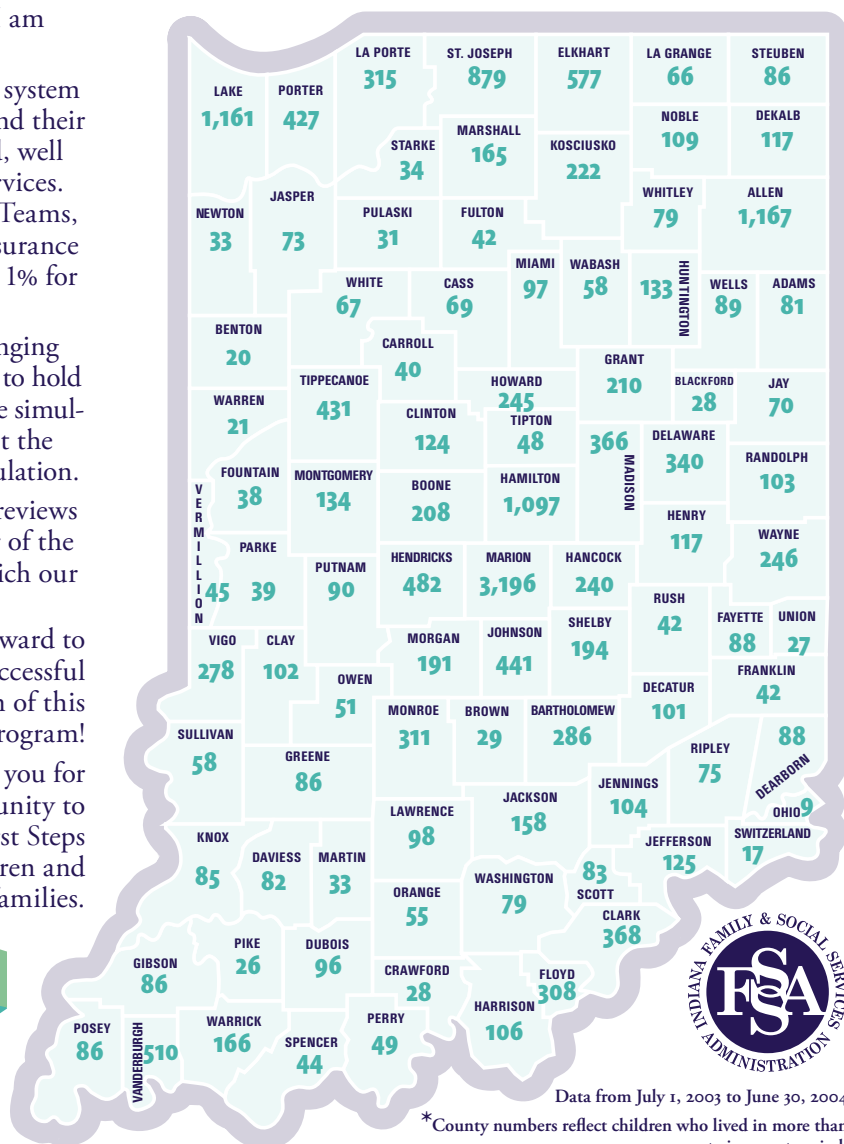
The ICC looks forward to the continued successful evolution of this great program!

Thank you for the opportunity to serve First Steps children and families.



Statewide Child Count

An aggregate total of 19,040* children received services through Indiana's First Step system.



Data from July 1, 2003 to June 30, 2004

*County numbers reflect children who lived in more than one county in report period.





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What is the Interagency Coordinating Council (ICC)?

Indiana's Interagency Coordinating Council on Infants and Toddlers (ICC), which was first convened in 1987, is appointed by the Governor to advise and assist Family and Social Services Administration (FSSA), the Lead Agency, in its responsibilities. Comprised of members representing parents of children with special needs, state agency groups, early intervention service providers, legislators, pre-service professionals, and others, the ICC is committed to holding the vision of First Steps Early Intervention Services in Indiana and to keeping abreast of issues, concerns, and trends which may affect First Steps in the future.

The ICC utilizes standing committees and task forces, developed around the basic components of early intervention, to identify current issues, gather information, and make informed and supportive recommendations to the Bureau. Family members, early intervention providers, Local Planning and Coordinating Council members and other interested community leaders serve on the committees and task forces of the ICC. With the help of these local representatives, the ICC can assist the Bureau in developing an early intervention system of the highest quality, which seeks to balance family-centered services with fiscal responsibility.

What is First Steps?

Indiana's First Steps System is a family-centered, locally-based, coordinated system that provides early intervention services to infants and young children with disabilities or who are developmentally vulnerable.

First Steps brings together families and professionals from education, health, and social service agencies. By coordinating locally available services, First Steps is working to give Indiana's children and their families the widest possible array of early intervention resources.

Families who are eligible to participate in Indiana's First Steps System include children, ages birth to three years, whom:

- Are experiencing developmental delays;
- Have a diagnosed condition that has a high probability of resulting in developmental delay;
- Are at risk of having substantial developmental delay as a result of biological risk factors if early intervention services are not provided.

First Steps is administered by the Bureau of Child Development within the Division of Family and Children of Indiana's Family and Social Services Administration (FSSA).

Members of the Indiana Governor's Interagency Coordinating Council on Infants and Toddlers

Valerie Strohl, Council Chairperson,
Parent, Zionsville

Joseph Anderson, Vice Chair,
Parent, Muncie

Parents:

Lori Crossley, Bloomington

Barbara Heffernan, Kokomo

Kathryn Morrison, Muncie

Early Intervention Providers

Anna Dusick, M.D.,

Riley Hospital for Children, Indianapolis

Jackie Garritano,

Tradewinds Rehabilitation Center, Gary

Karen Tyner,

Turnstone Center, Fort Wayne

Ginger Whitler,

Occupational Therapist, Evansville

State Agency Representatives

Sheron Cochran, Department of Education,
Division of Exceptional Learners

Judy Ganser, M.D., MPH, Maternal Child Health
Services, Indiana State Department of Health

Paul Hyslop, Indiana Department of Insurance

Phyllis Kikendall, FSSA, Healthy Families

OPEN, FSSA, Division of Disabilities and
Rehabilitative Services

Tim Maley, FSSA, Office of
Medicaid Policy & Planning

Cheryl Shearer, FSSA, Division of Mental Health

Personnel Preparation

Azar Hadadian, Ph.D, Muncie

Legislators

Vanessa Summers, State Representative
Indianapolis

Child Care

OPEN

Head Start

Jennifer Modesitt, New Richmond

What is the role of the First Steps Local Planning and Coordinating Councils (LPCCs)?

Thanks to having LPCCs in every one of Indiana's 92 counties, our state is making successful progress toward bringing together federal, state, local, and private funding sources to develop a coordinated, community-based, family-centered system of services. Each county's LPCC provides the authentic voice for early intervention services at the local level by identifying concerns, issues, and strengths unique to each community and then crafting a service delivery system that meets those locally identified needs.

In an effort to extend all that has been learned in early intervention, local LPCCs are working with each county's Step Ahead process, a pioneering framework for coordinating services for children ages birth to 13 and their families.



Our Mission:

To assure that all Indiana families with infants and toddlers experiencing developmental delays or disabilities have access to early intervention services close to home when they need them. This is accomplished through the implementation of a comprehensive, coordinated statewide system of local interagency councils called First Steps.

Our Vision:

Our goal is to serve infants and toddlers with or at-risk for special developmental needs by providing a family-centered, comprehensive, coordinated, neighborhood-based system of services for them and their families. To this end, we:

- ◆ Involve families in the development, implementation, and evaluation of the service system.
- ◆ Make services accessible and widely dispersed throughout the community.
- ◆ Offer choices to families that are typical of the choices available to all families of young children in their everyday routines, settings, and activities.
- ◆ Offer services that are culturally sensitive and tailored to individual needs of the child as well as family priorities.
- ◆ Offer services that exemplify best practices in early intervention and be accountable for the quality of these services by evaluating them in terms of process and outcome.
- ◆ Respect families by acknowledging that they are the primary constant in the child's life and by helping them to make choices as well as supporting them as they implement those choices, even when we disagree with them.
- ◆ Focus on prevention of, as well as intervention for, disabilities among infants and toddlers, keeping in mind that the ultimate goal is maximizing the potential of children so that they can function as contributing members of society as adults.
- ◆ Creatively use existing resources and seek additional resources to maximize service options for families and to fairly compensate staff providing services.



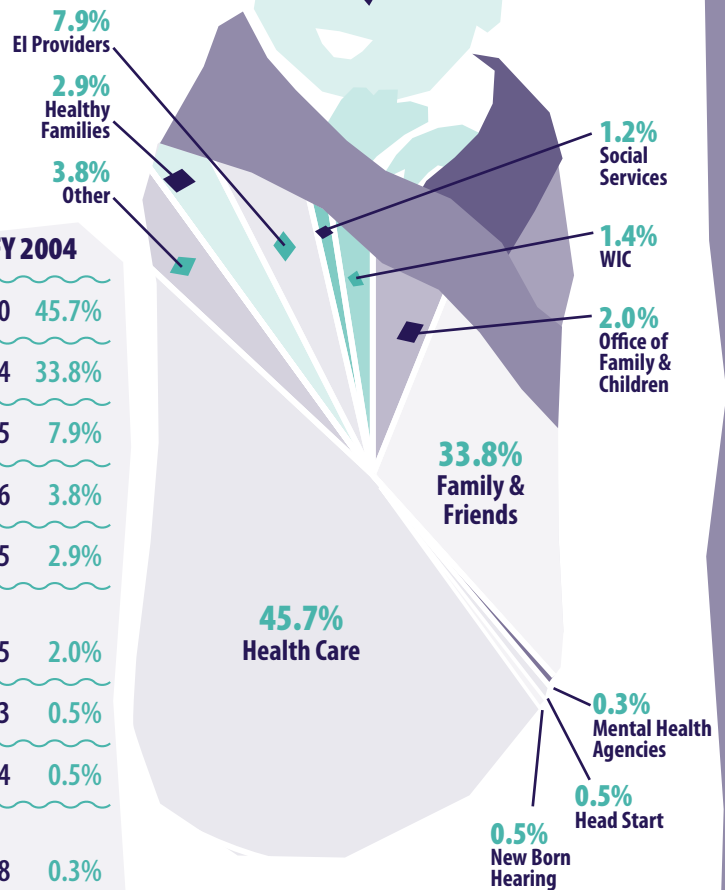
Child Find

Indiana First Steps

SFY 2004 Primary Referral Source

Primary Referral Source by Year

	SFY 2002		SFY 2003		SFY 2004	
Health Care	8,619	46.0%	9,588	48.2%	9,640	45.7%
Family & Friends	6,007	32.1%	6,455	32.4%	7,124	33.8%
El Providers	1,438	7.7%	1,226	6.2%	1,675	7.9%
Other	667	3.6%	747	3.8%	806	3.8%
Healthy Families	668	3.6%	575	2.9%	615	2.9%
Office of Family & Children	594	3.2%	491	2.5%	425	2.0%
Head Start	80	0.4%	100	0.5%	103	0.5%
New Born Hearing	-	0.0%	-	0.0%	114	0.5%
Mental Health Agencies	57	0.3%	33	0.2%	58	0.3%
WIC	375	2.0%	453	2.3%	298	1.4%
Social Service Agencies	215	1.1%	238	1.2%	244	1.2%



Eligibility*

Description	SFY 2002		SFY 2003		SFY 2004	
15% Delay in 2 or more Developmental Domains	2,740	22.0%	2,917	22.0%	3,747	28%
20% Delay in 1 Developmental Domain	6,729	53.0%	7,091	54.0%	6,995	53%
At Risk	683	5.0%	688	5.0%	597	4%
Medical Conditions	2,539	20.0%	2,390	18.0%	2,167	16%
Total	12,691		13,086		13,506	

Indiana First Steps Average Age at Referral

	SFY 2002	SFY 2003	SFY 2004
Average Age of Referral	13.8	13.8	13.9

*Includes only children who had an initial or annual eligibility determination

Supervision

Funding and Fiscal Responsibility

Indiana First Steps Early Intervention System facilitates and coordinates federal, state, local, and private resources for the payment of early intervention services for Hoosier families. The following funds are managed directly by Indiana First Steps.

All Sources of Funding for Early Intervention Services: Identification and Coordination of Resources

Sources of Funding	Amount of Funding	Services and/or Activities Supported by Each Source
Federal		
Federal Part C	\$7,818,892	All Services and Activities
Medicaid Federal	\$7,734,780	El Medical Services, Intake, Eligibility, Claims, Personnel Development & Training, Quality Assurance, Child Find, System Coordination
TANF Federal	\$11,349,107	El Non-Medical Services
State		
Early Intervention	\$17,778,588	All services and Activities
Medicaid State	\$3,335,268	El Medical Services, Intake, Eligibility, Claims, Personnel Development & Training, Quality Assurance, Child Find, System Coordination
SSBG State Supplement	\$5,000,000	All Services
TANF State	\$12,122,340	El Medical Services
MCH/CSHCS State	\$138,684	Intake and Eligibility
Local		
Private Insurance, Fees		See Cost Participation section on next page
Other(s), Non-Federal		
Family Cost Participation Co-payments	\$220,637	Services (Not IFSP, Evaluation, Service Coordination, Assistive Technology)
Total Early Intervention Support		\$65,498,295
Report Period 07/01/03 to 06/30/04		



Contact: by phone at 317-232-1144, 800-441-7837 (toll-free),
or web at www.state.in.us/fssa/first_step

Supervision cont'd

Complaint Data

Reporting Period	Total Number of Complaints	Number of Substantiated Complaints	Primary Provider Types	Federal Codes &/or Indiana Codes	Content of the Complaint	Finding	Resolution
July 1, '03 to June 31, '04	5	5	Service Coordinator (SC)	34CFR303.23 470IAC3.1-10-2	Service Coordinator Responsibilities Service Coordinator Responsibilities	Substantiated for both	Disenrolled
			Service Coordinator (SC)	34CFR303.23 470IAC3.1-10-2	Service Coordinator Responsibilities Service Coordinator Responsibilities	Substantiated for both	Probation*
			Service Coordinator (SC)	34CFR303.23 43CFR303.344 470IAC3.1-10-02 470IAC3.1-11-4	Service Coordinator Responsibilities Content of the IFSP (transition) Service Coordinator Responsibilities SC Responsibilities (transition)	Substantiated for all	Probation
			Service Coordinator (SC)	34CFR303.23 43CFR303.344 470IAC3.1-10-02 470IAC3.1-11-4	Service Coordinator Responsibilities Content of the IFSP (transition) Service Coordinator Responsibilities SC Responsibilities (transition)	Substantiated for all	Provider disenrolled self
			Service Coordinator (SC)	34CFR303.23 43CFR303.344 470IAC3.1-10-02 470IAC3.1-11-4	Service Coordinator Responsibilities Content of the IFSP (transition) Service Coordinator Responsibilities SC Responsibilities (transition)	Substantiated for all	Probation Supervision required

*SC supervisor was to submit supervision plan.

Cost Participation

The Indiana General Assembly passed legislation requiring the First Steps System to implement Cost Participation (cost sharing) for families with incomes over 350% of poverty on April 1, 2003. While this program is still in its infancy, First Steps Financial Management has noted the following:

- Total co-pays submitted to the Central Reimbursement Office (CRO) through 6/30/04 were \$432,427.41
- Total co-pays after refunds / adjustments at CRO through 6/30/04 were \$425,330.02
- Total co-pays used by the State to offset cost of services through 6/30/04 were \$220,637.45
- Total co-pays billed to eligible families through 6/30/04 were \$611,948.48

It is important to remember that families eligible for Cost Participation are not charged for Evaluation, Assessment, IFSP development and Service Coordination services. Eligible families are charged for on-going therapeutic services. At any time, a family may request their income be reviewed and updated.

Challenges still remain for the First Steps System regarding the billing of private insurance. Several insurance companies are working with First Steps to help define this process. Anthem has agreed to be the first company to accept claims from First Steps and billing will be implemented in the near future.

Peer Monitoring

One of the lead agency's key responsibilities is providing general supervision of programs and activities served with early intervention funding. This process includes an on-site review in each cluster. The program includes the review of clinical documentation, early intervention records, random reviews of provider billing and credential documentation and interviews with parents, providers and local planners. The peer review is used primarily to provide the local LPCC with information to guide their improvement planning and activities as well as to identify technical assistance needs at the local level. In 2004, Indiana First Steps became part of the National Center for Special Education

Accountability Measures (NCSEAM), a national project that utilizes a system self-assessment with a Focused Monitoring Approach to improve the quality of services and processes in early intervention.

Eligibility Determination (ED) Teams

At the end of June 2004, Indiana has initiated approximately 16 new Eligibility Determination (ED) Teams across the State. ED Teams are assigned to children as they enter the First Steps System and are responsible for completing initial evaluations, assisting in determining eligibility and developing initial IFSPs. ED Team members are an integral part of the child's IFSP team. Indiana's goal is to continue ED team implementation across the entire State.



Supervision cont'd

System Outcomes Project

Evaluation of Indiana's First Steps Early Intervention System

Data collection for the First Steps Outcomes Project began in November, 2002 following a series of state-wide stakeholder forums which defined the outcomes to be addressed. The first six outcomes were designed to

determine if children and families served by First Steps are experiencing important benefits. This report summarizes data collected during the period from January 1, 2003 to June 30, 2004. Data collected from families as they entered the system (N=13,033) and exited the system (N=9574) is summarized below by outcome.

First Steps Early Intervention System Outcomes

Outcome 1: Children attain essential and important developmental skills.

Over 87% of the children for whom both Entry and Exit information was available demonstrated an increase in the number of important developmental skills.

Outcome 2: Children participate in inclusive community activities, settings and routines.

Most of the children (83%) had participated in at least two different community activities and-or settings with their families in the past two weeks.

Outcome 3: Children (and families) are safe, healthy, and well-nourished.

At least 97% of the families reported the presence of all positive indicators for children's health such as seeing their doctor regularly and being up to date on immunizations; 99% reported knowing about and following recommended household safety measures such as the use of smoke detectors, car seats, and safe storage of poisons and firearms; and 99% reported having knowledge of proper nutrition.

Outcome 4: Families participate as members of the early intervention team and carry out recommendations that help them to help their child.

Over 99% of exiting families know and understand the First Steps process, including the purpose of the First Steps evaluation and IFSP, and felt they could participate as active members of their First Steps team.

Outcome 5: Families are connected to other families, associations, and organizations for emotional support.

At least 85% of the families reported knowing how to access at least one resource for emotional support.

Outcome 6: Families advocate by exercising their rights in requesting and choosing goals, services and supports.

Over 99% of families reported knowing how to exercise their rights, including how to problem-solve in situations when disagreements arose with their service providers.



Transition

Indiana remains committed to improving transition experiences for families and young children through the leadership of the State Transition Team and ongoing support of Indiana's Transition Initiative for Young Children and Families. Joint funding from Family and Social Services Administration, and Indiana Department of Education, Division of Exceptional Learners supports Indiana's Transition Initiative through the Unified Training System. This collaboration supports a state transition coordinator and regional facilitators to provide technical assistance, training, and support to address transition issues to Indiana's ninety-two counties. First Steps providers and public schools are required members of the local transition teams that also include Head Start and other agencies that transition young children and families. During this reporting period the transition staff worked with multiple school corporations, First Steps Early Intervention staff, Head Start representatives, and families to improve transition.

Another major focus of the state transition coordinator

was to review local interagency agreements to identify procedural weaknesses and provide technical assistance on writing or re-writing local interagency agreements. Fifty-six transition agreements were identified representing 68 special education cooperative/school systems and 65 First Steps clusters and/or counties.

In October, 2003, agency representatives from Department of Education, Bureau of Child Development, Indiana Principal Leadership Academy, Indiana Association of Child Care Resource and Referral signed a position statement on transitions of young children affirming the necessity of a collaborative team approach within a community. That approach focuses on advanced planning and preparation of the child, family, and staff in transition planning and publicizing the availability of the state coordinator to assist in developing local transition teams. The statement was published and widely distributed.

The transition initiative links transition teams and others to transition materials and products at:

<http://www.indianatransition.org>.

Natural Environments

Numbers of children receiving authorized services

Indiana's First Steps has long embraced the federal mandate of providing services in a child's every day routines, activities, and places. In 2004 Indiana provided 94% of its services in the child's regular settings.

Indiana continues to place high emphasis on the implementation of activities that will reduce the number of days from referral to IFSP. Any IFSP over the 45 days must be documented and signed by the Service Coordinator and Parent/Caregiver. Indiana continues to improve upon compliance with the 45-day timeline.

Indiana's average number of days from referral to IFSP have steadily decreased from 38.3 to 37.9.

Service Type	# of children	Service Type	# of children
Assistive Technology	1,474	Other Related Services	143
Audiology	3,269	Physical Therapy	7,081
Developmental Therapy	8,450	Psychology	361
Health Services	0	Service Coordination	17,524
Interpreter Services	178	Social Work	235
Medical	3	Speech Therapy	10,725
Nursing	46	Transportation	20
Nutrition	792	Vision	65
Occupational Therapy	6,682		

Family-Centered Services

Family to Family Initiative

Family to Family (F2F) continued to grow and expand in 2003–2004. Through outreach and networking activities, F2F Regional Facilitators and parent Points of Contact accomplished the following:

- Over 11,000 parent packets were distributed, 782 direct contacts were made with First Steps families. 52 parent point of contacts (POCs) were active during this contract period.
- 182 members were registered on the F2F list serv. From October 1, 2003 to September 30, 2004, 2,794 messages were posted to the list serv.
- 20 new families interested in Local Planning and Coordinating Council (LPCC) membership were identified.

Family to Family is committed to working with existing systems, groups, and initiatives to develop a comprehensive approach to supporting the needs of families.

Parent Leadership Team

The ICC was the recipient of a Parent Leadership grant in May 2004 and a team of ICC parents developed a plan to

build on the existing foundation of family involvement in the First Steps system. A series of family celebrations were planned in several communities around the state designed to:

- Provide networking opportunities for First Steps families
- Gather feedback from families for the ICC
- Connect families to local resources
- Identify more parent leaders
- Connect with under-served populations

The results of the gatherings will be available in the next reporting period.

Family Involvement Fund

Families who participate in various learning opportunities report growth in information and knowledge that they will use to better support their children with special needs. Eight hundred and fifty-five (855) families accessed the family involvement fund to support their educational activities during this grant year.

A Message from the Part C Coordinator—Dawn Downer

This year, like many before, Indiana has continued to build on the success of its Early Intervention system. This year's primary focus has been to support quality improvement initiatives to reinforce our current system. We are pleased with the current data regarding child and family outcomes. In addition, on-site monitoring of program compliance supports our progressive approach to early intervention services.

Our emphasis in the coming year will continue to be data collection and ongoing quality improvement of service

delivery as we work together to meet the needs of Indiana's families and children. This objective will be accomplished by delivering quality direct service, ongoing provider education and ongoing needs assessments. Together with parents, providers, state staff, and community members, we have come together to strengthen a system that continues to lead the nation in early intervention programs. As the Part C Coordinator, I am very pleased to share with you the annual report of the ICC.